

Second Meeting of Ad Hoc Expert Group on Institutional Care Reform 28 April 2009

The meeting was attended by the following Members: Jan PFEIFFER, Ask ANDERSEN, Ines BULIC, Josee VAN REMORTEL, Anne-Sophie PARENT, and Luk ZELDERLOO. The European Commission was represented by Michael RALPH (Cab Spidla), Jana BIEDERMANNNOVA (Cab Spidla), Silvio GRIECO (DG EMPL), Juergen SCHEFTLEIN (DG SANCO) and Marek STAVINOHA (DG JLS).

Programme:

1. Introduction.

Mr. RALPH introduced himself and excused the absence of Mr. JARAB. Other members of the Expert Group and Commission representatives introduced themselves shortly.

2. Agenda and approval of previous minutes.

Mr. RALPH presented the agenda. Minutes of the last meeting were approved without further comments. It was decided that comments to the 2nd meeting minutes will be sent only to the secretariat (Mr. GRIECO) and then only the final version will be sent around.

3. Progress of individual contributions from the Members.

Ms. BULIC presented the first contribution from ECCL, which was previously sent by email to the Members. The document was positively welcomed by the Members as a good starting point, however it was pointed out (by Ms. PARENT) that the document represents mainly the point of view concerning people with disabilities and that its findings will need to be adapted to the holistic approach of the final report.

4. Discussion on the Report: structure and timing of the first draft.

A first draft structure of the report was presented by Mr PFEIFFER to be discussed. There was a general agreement on the general structure and the division into chapters: foreword, executive summary, descriptive part, broad policy recommendations, specific recommendations to the Commission. Then a constructive discussion on the content of each chapter followed.

4.1 Foreword. It was agreed that the Report will have a foreword by Commissioner Spidla, which will give a positive political message, mainly explaining why a holistic approach to institutional care reform in Europe is needed, what has to be changed and what the role of the EU is.

4.2 Executive summary. It was agreed that an executive summary will synthesize the main findings of the Report.

4.3 Descriptive part. It was agreed that this chapter will start with a definition of institutions for the purpose of the report. The discussion between the Members showed that it will not be easy to find a common definition. Ms BULIC brought up the example of the study "De-institutionalisation and community living: outcomes and costs", for which

purpose institutions were considered those residential settings with more than 30 "clients". However, it was clear that the different purpose of the Report will bring to work on different kind of definition, more qualitative than quantitative (Ms. BULIC and Mr. ANDERSEN). There was a common agreement that the report will refer rather to the "institutional culture", where the size and the structure of institutions are only the most visible phenomenon. How to consider the size of institutions remain the most controversial matter. Mr ZELDERLOO said that there is enough evidence that the larger is the setting, the less chances there are to have human and quality services, participation, and inclusion in the community. Some problems were on the It's difficult to have a unique definition of institution, mainly because of different cultural and legal frameworks in Member States. For instance, in some Countries providers of community based services are classified as institutions because of the legal framework. The Report will refer rather to the "institutional culture", where the institutions as "buildings" are only the most visible phenomenon. The problem definition has to be based on a human rights approach: "institutional care" means segregating settings, where persons are treated as patients and not as human beings fully enjoying human rights, where persons are ignored, exposed to discrimination and abuse, excluded from the community.

However, the small scale as such is not a guarantee of good services in the community.
In this chapter, it would be good to have references to academic sociology and psychology literature on what is commonly meant with institutions, and how the concept has historically evolved.

Descriptive part

All the Members agreed that it has to be cleared out what is meant by the word "institution" (its not only about the number of clients (end-users)).

Mr. Anderson pointed out, that definition of the word "institution" is something the Members should really focus on.

Mr. SCHEFTLEIN had stressed that the quality criteria are much important then the size. (there could be 29 people living in a large setting in compare to the 30 people living in a small community based institution).

Mr. Anderson mentioned that the big number of service users in the setting usually means that participation in the society is more difficult.

Structure of the descriptive part

There was a question set by Mr. Pfeifer about the structure of the descriptive part. (if it's better to have 4 separate small chapters of joint analysis.)

Mr.Zerledloo pointed out that its necessary to start with positive message..."what we really want." Afterwards it will be easier to describe what "we don't want".

According to other suggestions it would be efficient to start with the description of the current situation.

Mr. Pfeifer pointed out that political message should be a part of the foreword

Mrs. Van Remortel is in forward of separate chapters (There are difference between categories of children we should show the differences)

Mr. Zerdeloo pointed out that for instance in Romania there has always been a problem in putting people in categories (a mixture of grounds disabled, orphans).

Mrs. Parent pointed out that, if there is a particular group with insufficient data available, it shouldn't be neglected for that reason. She had also stressed that the definition of the word "institution" wouldn't match in different Member States.

Mr. Zerdeloo- set the example that every French service provider its called an "insitutiotion", Its difficult to find reliable data about how the people live there. It's difficult to filter out what kind of setting it's provided.

There was an agreement among the Members that the experts will send the all available data to the members of Commission. And according the results it will be decided how the draft should be structured.

Content of the descriptive part

Ms. VAN REMORTEL mentioned the danger of "horizontal institutionalisation". The building was reconstructed but nothing changed in peoples minds.

Mrs. Parent pointed out that "the disgregation" would be more precise expression for what the Members are trying to achieve then the word "de-institutionalisation"

Mr. Zelderloo stressed that there has been study conducted in England showing that there is less chance of maintaining the quality of service provided in a larger setting. He had also pointed out the positive intentions (of the founders of the providers- 30 years ago), so it's desirable not to be too critical.

Mr. Pfeiffer had added that it's necessary not to criticise but on the other hand "not to be blind."

Ms. VAN REMORTEL mentioned the necessity to learn out of failures.

Summary

In the third part of the Draft it should be mentioned common features, common challenges good and bad examples, there are also to be mentioned several scenarios which doesn't work

Economical assurance

Mr. Ralph had set a question about economical assurance of the whole process. "Its impossible to have a report without economical idea behind it."

Mr. Zelderloo mentioned the difference (in the way of funding) between aging sector, which has been privatised and the disability sector which is provided by state authorities

Mr. Anderson pointed out that the situation needs to be described dramatically to counterbalance the financial agreement.

Mr. Zerledloo had mentioned following points

-financial incentives

-overlap in funding

- it's necessary too realise that for 80 % of clients the costs will be lower-for the remaining 20% they will increase

Mr. Pfeifer concluded that the legislative framework and quality control have to be a part of the report (in the broad policy recommendation chapter).

Mr. Zerldeloo-the challenge is to bring support to the people instead of bringing people to the support

-majority of the workforce has been trained under another model.

-also pointed out that this is a reform of the whole sector (stated an example of the structural reform in the steel industry) so "money should be put on the table!"

Link to the international documents

Mr. Stavinoha mentioned the link to international documents

Mr. Pfeifer concluded, that small chapter should be devoted to interpretation on various conventions (international documents- UN convention of disabilities and others)

3.2. The timing of the first draft

- the whole draft has to be completed by the end of June

-Mr. Grieco will circulate the first skeleton in 2 weeks

-the next meeting is going to take place either on 23 June (Mrs. *VAN REMORTE* wouldn't be able to attend) or on 30 June. It is necessary to check the available dates with Jan Jarab as soon as he will return back.

4. Progress of the parallel working group on the use of Structural Funds for de-institutionalisation in Bulgaria

Short introduction by Mr. Grieco, next meeting of the group is scheduled at 12 May 2009

Ms. Bulic mentioned that there are some funds available in DG Education and Culture, which might be used for retraining the staff

Structural funds

Michael Ralph's introduction about structural funds

.....(to by added by Michael Ralph)

Mr. Anderson set the question about how monitoring authorities could be involved in the process. He suggested if the idea of having session on this topic could be considered.

5. Other parallel policy processes

-WHO European branch -2 months ago there was a meeting in Budapest on the same topic, focused on children with disabilities, DG SANCO is in touch with them

There was a clear agreement around the table that it's necessary to bring all the processes going on together. Mr. Grieco will inform them, so they can make use of our report.

Mr. SCHEFTLEIN ...Conference in Prague in May-destigmatisation and mental health

Mr. Ralph informed about the Mission of the Commissioner to Greece and its results (there was a problem with sustainability of what has been already achieved)

6. Any other business

Mr. Grieco informed the Members about Network of disability experts, they will provide DG EMPL with updated information. In June they will have this information about situation in Member States completed (valuable source of data for the Draft).